

<b>Institution: Queen's University Belfast</b>		
<b>Unit of Assessment: UoA3</b>		
<b>Title of case study: Transforming supportive cancer care for patients and families in Northern Ireland.</b>		
<b>Period when the underpinning research was undertaken: 2008- Current</b>		
<b>Details of staff conducting the underpinning research from the submitting unit:</b>		
<b>Name(s):</b> Dr Olinda Santin	<b>Role(s) (e.g. job title):</b> Senior Lecturer	<b>Period(s) employed by submitting HEI:</b> Olinda Santin 2009- Present
Dr Gillian Prue	Reader	Gillian Prue 2012-Present
<b>Period when the claimed impact occurred:2014-Present</b>		
<b>Is this case study continued from a case study submitted in 2014? N</b>		
<p><b>1. Summary of the impact</b></p> <p>Our research has transformed supportive cancer care for patients and families in Northern Ireland. This research was instrumental in the launch of a GBP1,300,000 project 'Transforming cancer follow up' for Northern Ireland (NI). The evidence led to the implementation of a new model of cancer patient follow up, termed 'A recovery package', which included a holistic assessment, a treatment summary record, an individualised pathway and rapid entry back into the system. This model improved experience for over 10,000 patients by improving self management and reduced anxiety, travel time to appointments, need for dual speciality appointments and reduction in surgical review waiting times. This research also led to the co-design of an online support system <a href="http://www.cancercaringcoping.com">www.cancercaringcoping.com</a> that was integrated into services across NI providing support to 10,000 families per year and which has been adapted to support families affected by cancer in Australia and Vietnam.</p>		
<p><b>2. Underpinning research</b></p> <p>In 2007, there were UK-wide concerns within the National Health Service (NHS) regarding the unmet healthcare needs of cancer survivors and the inadequacies of the traditional medical model of cancer follow up. These concerns led to a call for research to explore the needs of cancer survivors.</p> <p><b>Research with cancer survivors</b></p> <p>In 2008, Santin et al. carried out a population-based survey of a random sample of 600 survivors of colorectal cancer (<b>R1</b>). Forty percent of respondents reported one or more unmet health and social care needs such as fatigue, fear of recurrence, information deficits and financial difficulties with associated low quality of life. This was followed in 2010 by a comparative analysis of the health and well-being of all cancer survivors compared to the general population. In this study, 289 cancer survivors who were 2-15 years post-treatment were randomly sampled from the Northern Ireland Cancer Registry and matched to randomly selected non-cancer patients (<b>R2</b>, <b>R3</b>). Survivors reported significantly poorer health than the general population in terms of physical functioning, emotional functioning, general health perception and social functioning. Further research with this sub-group (<b>R3</b>) demonstrated that, compared with other survivors, they experienced a significantly greater number of co-morbidities, lower physical health and mental health scores, greater overall health service use and more unmet needs. Overall, this research showed that cancer survivors have a lower quality of life and more unmet needs than the general population but that there was considerable variation between individuals and also a variety of different needs. e.g. mental health and financial needs. This indicated that uniform routine follow-up, focused on medical issues was an inefficient way to meet the diverse needs of this population.</p>		

### Research with informal cancer carers

In 2010, little was known about the impact of cancer on primary caregivers and their subsequent health care needs. Cancer survivors (**R2**) were asked to invite their informal carer to take part in a survey measuring health and well-being (**R4**). Ninety-eight carer-survivor dyads returned completed questionnaires, which were representative of the NI population.

Approximately 80% of carers reported monitoring survivors and accompanying them to activities and appointments; whilst about 20% engaged in direct caring in relation to mobility or personal care. Over a quarter spent more than 22 hours per week providing care for survivors. There were no significant differences in physical health and mental health summary component scores or number of reported illnesses between survivors and informal carers. Overall, compared to normative scores cancer carers had significantly poorer physical and mental health than carers of other chronic conditions. As part of the same study (**R4**), semi-structured interviews were conducted with a purposive sample of 24 cancer professionals to identify the care needs of carers. They reported that carers' information needs were largely unmet and that the existing service provision does not provide the opportunity for carers to voice their concerns or issues with clinical staff.

Santin then developed and tested a web-based resource to support carers (**R5**). Twenty-five caregivers and 16 stakeholders worked in partnership and co-designed a prototype web-based resource. Fifty-five cancer caregivers completed an evaluation of the resource, involving an online survey and 10 follow-up telephone interviews. Ninety eight percent of carers rated the resource as excellent, useful, and easy to use. The web-based videos were regarded as engaging and more readily accessible than written information. The resource provided relevant information, potentially reducing isolation and uncertainty (**R5**). Santin has conducted a series of qualitative studies involving over 100 stakeholders to develop cultural and contextual adaptations to the resource for use in Vietnam and Australia (**R6**).

### 3. References to the research (indicative maximum of six references)

- R1. **Santin, O.** Murray, L. **Prue, G.** Gavin, A. Gormley, G. **Donnelly, M.** (2015) Self-reported psychosocial needs and health-related quality of life of colorectal cancer survivors. *European Journal of Oncology Nursing*, 24, 121-129. DOI: [10.1016/j.ejon.2015.01.009](https://doi.org/10.1016/j.ejon.2015.01.009)
- R2. **Santin, O.** Mills, M. C, Treanor. **Donnelly, M.** (2012) A comparative analysis of the health and wellbeing of cancer survivors to the general population. *Journal of Supportive Cancer Care*.20.10. 2545-2552 . DOI: [10.1007/s00520-011-1372-9](https://doi.org/10.1007/s00520-011-1372-9)
- R3. Treanor, C. **Santin, O.** Mills, M. **Donnelly, M.** (2012). Cancer survivors with self-reported late effects: their health status, care needs and service utilisation. *Psycho-oncology*. 22. 2428-35. DOI: [10.1002/pon.3304](https://doi.org/10.1002/pon.3304)
- R4. **Santin, O.** Treanor, C. Mills, M. **Donnelly, M.** (2014) The health status and health service needs of primary caregivers of cancer survivors: a mixed methods approach. *European Journal Cancer*. Volume 23, Issue 3, pages 333–339. DOI: [10.1111/ecc.12157](https://doi.org/10.1111/ecc.12157)
- R5. **Santin O,** McShane T, Hudson P, **Prue G.** Using a six-step co-design model to develop and test a peer-led web-based resource (PLWR) to support informal carers of cancer patients. *Psycho-oncology*. 2018 Dec 29. [https://doi.org/10.1002/pon.4969-](https://doi.org/10.1002/pon.4969)
- R6. **Santin, O.**, Jenkins, C., Nghiem, H.L., **Prue, G.**, Reid, J., Lohfeld, L. and Ho, H.T., 2020. The development of a web-based resource to provide information and psychosocial support to informal cancer carers in hospitals in Vietnam. *Psycho-oncology*, 29(5), pp.920-926. <https://doi.org/10.1002/pon.5368>

**4. Details of the impact** (indicative maximum 750 words)

Research by Santin et al (R1, R2, and R3) led to improvements in health services for over 1,000 cancer survivors in NI every year, which equates to 6,000 since 2014 (**S1, S2 & S3**). The research first informed a **process of engagement** with stakeholders initiated by Macmillan Cancer Care, including the Health and Social Care Public Health Agency, all five Health and Social Care (HSC) Trusts and Northern Ireland Cancer Network (NICAN), and the Northern Ireland Cancer Consumer Forum and the research team which focused on service development solutions to the problems. Secondly, on the basis of this partnership, Macmillan Cancer Care agreed to invest GBP1,300,000 in the 'Transforming Cancer Follow-up Programme' (**S4**) in NHS of NI. This programme produced the following benefits:

- The creation of **6 new fixed term 3-year senior NHS posts** responsible for service development of a new model of follow-up care and **3 new permanent clinical posts** (2 colorectal nurse specialists in the Northern Health and Social Care Trust (NHSCT) and a Specialist GI dietician to implement the model (still in post at time of submission) (**S1**).
- By 2015, this new model of 'a recovery package' led to 58% of newly diagnosed breast cancer patients entering the Self-Directed Aftercare (SDA) pathway (**S2,S5**). As a result, approximately 60% (1,478 per year or approximately 7,500 since 2014) of newly diagnosed breast cancer patients in NI are now discharged to SDA and are receiving information and support tailored to their needs. Staff identified a number of benefits:
  - Better informed patients with empowerment to self-manage (**S2,S3,S5**)
  - Less travel for patients and less time spent waiting at clinics (**S2,S5**)
  - Reduced anxiety (**S2,S5**)
- An independent impact evaluation of 'the recovery package' on **Northern-Ireland programmes** for breast, prostate, colorectal, haematological, gynaecological, dermatological, renal and head and neck cancer services (**S2,S5**), demonstrates direct improvements in the care of at least 1000 cancer survivors across all of NI every year (**S3**), i.e.:
  - Over 1,000 new patients allocated to the Self Directed Aftercare pathway (including 60% of breast cancer patients) between April 2015 and March 2016 with the pattern continuing annually (**S3**).
  - A 40% (approximately 1000 patients) reduction in dual speciality follow-up (**S3**).
  - 2,724 (40%) reduction in breast cancer patients waiting for surgical review (**S3**).

Furthermore, in one specific Trust the improvements for approximately 3,400 patients per year have meant a

- 24% (between 2015 and 2018) improvement in accessing a clinical nurse specialist (**S1**)
- 10% (between 2015 and 2018) improvement of patients given information about support and self-help groups (**S1**)
- 11% (between 2015 and 2018) improvement in number of patients given access to financial help and benefits (**S1**)
- 10% (between 2015 and 2018) improvement in the number of patients who feel they had been given enough care and support after treatment (**S1**)

The independent evaluation (**S2,S5**) also attested to the implementation of health and wellbeing events across all HSC Trusts to help people affected by cancer and their family to self-manage their condition with evaluation demonstrating that patients who attend

- are more confident to challenge information
- make informed decisions
- cope with the physical and emotional impact of cancer and its treatment (**S1,S2**)

**Research by Santin et al. (R4,R5) has also led to improved service provision for caregivers of cancer survivors in Northern Ireland, Australia and Vietnam.**

The **second phase of research (R4,R5)** involved the co-design of a new online support for informal cancer carers 'Cancer Caring Coping' ([www.cancercaringcoping.com](http://www.cancercaringcoping.com)).

Cancer Caring Coping is a one-stop, online, multi-media website tailored to support carers from diagnosis to possible bereavement, supplemented by advice from professionals. The resource also acts as a portal to local voluntary, charitable, health, and social care services (**S6**). The development of the resource was designed in partnership with 2 HSC Trusts, and UK cancer charities including The Northern Ireland Cancer Consumer Forum, Macmillan Support and Information Centre, Men's Health Forum in Ireland, Cancer Lifeline, NI Cancer Network, Charis Cancer Care, Pancreatic Cancer Support and Action, together with 79 cancer carers.

Based on this research and partnership, NHS providers in all HSC Trusts, at cancer diagnosis, now routinely provide caregivers with promotional material signposting over 10,000 caregivers per year to the resource (**S1**). Initial evaluation indicates that the resource is able to meet the information needs of informal cancer carers (**R1**). The resource has also been included within an essential care and cancer tool kit launched by the European Association Working For Carers (Eurocarers) (**S7**). **This model of support for carers has been adopted internationally with a Vietnamese and Australian version of the resource underway (S8,S9).**

Santin and the QUB research team, in partnership with cancer service providers and the state Cancer Councils in Australia, are delivering an Australian version of the 'Cancer Caring Coping' resource, with a plan for nationwide implementation by cancer services in Australia in 2021. This is funded by the Cancer Council of Australia (**S8**).

A similar partnership is underway with 5 cancer hospitals across Vietnam. This work has led to the development of a cancer research consortium bringing together experts who have co-designed an adaptation of the 'Cancer Caring Coping' resource for nationwide use (**S9**).

#### **5. Sources to corroborate the impact** (indicative maximum of 10 references)

S1 Testimonial, Cancer Information Manager, Northern Health and Social Care Trust.

S2 Evaluation of the Transforming Cancer Follow-Up Programme. Wave 1 Evaluation Report. August 2013. Price Water House Cooper.

[https://www.macmillan.org.uk/documents/aboutus/research/researchandevaluationreports/ourresearchpartners/macmillantcfuevaluation-finalreport\(260813\).pdf](https://www.macmillan.org.uk/documents/aboutus/research/researchandevaluationreports/ourresearchpartners/macmillantcfuevaluation-finalreport(260813).pdf)

S3 Burns, C.Thompson, MJ. (2016) Sustainable Cancer Service Redesign.

[https://www.macmillan.org.uk/images/sustainable-cancer-service-redesign\\_tcm9-298128.pdf](https://www.macmillan.org.uk/images/sustainable-cancer-service-redesign_tcm9-298128.pdf)

S4 Transforming Cancer Follow Up Launch 2014 .

<http://www.transformingyourcare.hscni.net/transforming-cancer-follow-up/>

S5 Macmillian Cancer Support 2015 – Evaluation of the Transforming Cancer Follow-Up Programme in Northern Ireland. Final Report.

<https://www.macmillan.org.uk/documents/aboutus/research/researchandevaluationreports/ourresearchpartners/tcfufinalreportfeb2015.pdf>

S6 Cancer Caring Coping web resource: <https://www.qub.ac.uk/sites/CancerCaringCoping/>

**Impact case study (REF3)**

S7 EUROCARERS, The essential care and Cancer Toolkit. <https://www.eurocarers-cancer-toolkit.eu/references/>

S8 Testimonial, Head of Cancer Information and Support Services at Cancer Council Victoria, Australia.

S9 Testimonial, Hanoi University Public Health, Hanoi University of Public Health, K3 National Oncology Hospital Hanoi, Ho Chin Min City Oncology Hospital, Danang Oncology Centre, Can Tho Oncology Hospital, Hue Medical and Pharmaceutical University. Oncology Centre Hue, Vietnam.